

END-OF-LIFE CARE

Mr. WYDEN. Mr. President, late last week, the Nation witnessed the end to a saga that was heartrending not only for the medical circumstances of the young woman at its center, but for the tragic controversy that surrounded it.

The Congress has spoken once about Terri Schiavo, and in the near future the Senate's Committee on Health, Education, Labor, and Pensions is expected to hold hearings about one of the issues Ms. Schiavo's situation brought to the spotlight: the rights of the incapacitated and our society's responsibility toward that community. I hope the Congress will now begin a thoughtful examination of this and issues relating to end-of-life care. For that reason, I rise today to urge and encourage caution as the Senate moves forward.

George Washington called the Senate the saucer to cool the legislation. I would say the Senate, in fact, must cool its own passions before proceeding. The alternative is unacceptable. The Senate must not revisit the dangerous zero-sum game of 2 weeks ago, creating a false debate between those who seek protection and those who desire choices and actually sacrificing one of those rights to secure the other. This body's responsibility is to find solutions that preserve both. Protecting the vulnerable and preserving end-of-life choices are not mutually exclusive. Advocates for the disabled are right when they say that losing physical or mental capacity must not deprive anyone of their rights even if they have not had or taken the opportunity to make their treatment and wishes known.

There is legitimate cause for worry that the majority of our population might give short shrift to the real rights of a minority group. Journalist James Taranto summed it up well when he said:

It was natural for an able-bodied person to think: I wouldn't want to live like [Terri Schiavo]. But someone who is disabled and abjectly dependent on others was more apt to be chilled by the talk of her "poor quality of life" and to think: I wouldn't want to be killed like that.

Let us reject any legislative effort that springs from these false choices diminishing the rights of the incapacitated and all Americans. New Federal efforts may have the goal of protecting rights, but they may have the real effect of engineering outcomes with little regard to a patient's true interests. Instead of courting this risk, the Senate should seek to empower the disabled and all Americans.

My sense is that momentum still exists in this body to act unwisely in a way that will produce more government and fewer choices for all Americans at the end of life, so let me be clear. I intend to oppose any congressional fiat that disempowers our citizens—disabled, abled, incapacitated, or otherwise. I will oppose any such dictate that restricts the choices for our

citizens at the end of life and grows the role of government instead.

In the last 2 weeks, Americans have overwhelmingly cautioned the Congress against government mandates for the end of life. Many voices are speaking. Some have been shouting. If the Senate can't yet distinguish the country's clearly stated desire, then this body ought to fall silent and listen harder before acting.

In many ways, this is the central question of our time: whether the Federal Government will seek to expand its reach when the citizens wish for more individual empowerment. Presented with that question 2 weeks ago, the Senate got it wrong. The American people have made it clear that moving forward, there ought to be a course correction. True leaders will approach these choices dispassionately with a set of impartial principles.

I will spend a few minutes discussing what I think those principles ought to be. First, the Senate should help empower Americans to make their own choices about the end of life, whatever those choices should be. Policy ought to be grounded on the principle that Americans setting their dining room tables, in their kitchens, discussing their wishes and their fears with their loved ones, and asking in the end that government should make sure their desires are carried out. The choices they have to discuss—discuss in their homes and in their workplaces—ought to be expanded, not weakened, by Government and bureaucracy. Our policies should help their wishes to be honored by their families and their health care system—their lives sustained as they wish or unwanted treatment ended as they wish.

Second, as the Senate looks at the end of life, the Senate needs to look at the entire picture. End-of-life care is more than respirators and feeding tubes and even more than living wills. The Senate has to get beyond today's hot-button questions. The Senate ought to look at the fundamentals: conquering pain, expanding hospice care, capping the great potential of comfort care, which is known as palliative care. Supporting new ways to treat a very ill patient physically, spiritually, and emotionally, long before the last days of life, is a good use of the Senate's time.

Third, the Senate must address end-of-life issues with respect for constitutional boundaries that have been dangerously dismissed to date. For the last 2 weeks, issues of separation of powers and federalism have received virtually no attention. The Senate needs to reflect on the roots and the reason of federalism, which has given the States control over medical practice for more than 200 years. There is a line the Senate must not cross again. Beyond that line are the constitutional rights of States and, ultimately, the rights of our citizens.

Those individual rights, or citizens rights, ought to be the Senate's first

guideline in moving forward. I realize the temptation is to frame the debate entirely in terms of the heartbreaking situation of Ms. Schiavo. I believe it would be a mistake, however, to base Federal law on the basis of the tragic chaos that transpired in that woman's family. The Senate cannot jump in now and play medical czar to predetermine the outcome of every similar case. Our responsibility is to help individuals and their families to avoid the compounded tragedy that occurred in that family.

Helping Americans make their wishes clear is paramount. There are a variety of ways this can be done. The 50 States and the District of Columbia have made provisions for the declaration of individual choices, often through the creation of an advanced directive or a living will. If the Congress acts, it certainly should not thwart State laws in this area. Our goals should be to increase awareness and access and to look for ways to aid the enforcement of those wishes of families and the health care system.

Certainly, living wills should be encouraged, and thousands of Americans now are looking to fill these forms out. But in many instances, frequently that living will, a piece of paper, is not enough. Too often people will still be confused about an individual's real desires. Too often the language will not be clear or subject to misinterpretation. The bioethicist Carl Schneider of the University of Michigan said he is "appalled" at the number of people who are advising the public that a living will alone will be sufficient. He states:

Living wills often do not work.

So the national discussion about end-of-life choices should include information that will ensure that wishes be carried out, not just stated. As national leaders, those of us in the Senate can promote this discussion.

Most folks looking into advanced directives today seem to think they can just avoid a controversy through a living will. Maryland Attorney General Joe Curran recently said that 27,000 people in his State alone downloaded the forms over a period of 7 days. That is compared with 600 downloads during just 1 week in January. But, as I have indicated today—and I know it will be surprising to many Americans—the reality is the laws vary with respect to living wills and advanced directives, and often they do not ensure enforcement of a patient's wishes. Therefore, Americans need to know about vital mechanisms in addition to the living will. For example, the health care proxy, which designates one person if a person becomes incapacitated, is another approach that may be a value to our citizens because it leaves no doubt as to who speaks for those who cannot speak for themselves.

There are other options that can help ensure the effectiveness of an advanced directive. My home State uses a document called a "POLST," which stands